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ABSTRACT

This paper reviews the literature and presents a bibliography on the situation of people with mental retardation in Bangladesh. It begins with a review of the history of mental retardation in East Bengal, India (now Bangladesh) from the 1770s onwards but focuses on the development of disability information and formal services since the creation of Bangladesh in 1971. A listing of 20 disability surveys conducted in the region since 1961 is provided. It stresses, however, the very modest amount of information available on the lives of Bangladeshis with mental retardation in both rural and urban areas. Currently, children with mental retardation are either casually integrated in ordinary schools, in planned mainstreaming programs, in special schools, or in home teaching programs. A special need is seen for research on the lives, thoughts, and practices of families with a mentally retarded member. The bibliography is in three sections: Section 1 includes 80 items on mental retardation and childhood disabilities in Bangladesh; Section 2 includes 35 items on other relevant material such as child rearing, rural women, and primary education in Bangladesh; and Section 3 provides 72 historical references on mental retardation in East Bengal 1771-1971. (Contains 187 references.) (Author/DB)

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MENTAL RETARDATION, FAMILIES & EDUCATION

IN BANGLADESH.

Introduction & Bibliography.

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ABSTRACT

The Introduction to this paper sketches the historical background of mental retardation in East Bengal, India, from the 1770s onwards. More detail is given of the development of disability information and of formal services since the creation of Bangladesh in 1971. Twenty disability surveys are listed, between 1961 and 1995. The paper reviews the modest amount of information available on the lives of mentally retarded Bangladeshis in rural and urban families and communities. Some mentally retarded children are casually integrated in ordinary schools, some are in planned mainstreaming, some are being educated in special schools, some are in home teaching schemes. For more effective service development and resource transfers, detailed information is needed on the lives, thoughts and practices of families with a mentally retarded member. The Bibliography is in three sections: [1] mental retardation and childhood disabilities in Bangladesh (80 items); [2] other relevant material, e.g. child-rearing, rural women, primary education (35 items); [3] historical references on mental retardation in East Bengal 1771-1971 (72 items).

MENTAL RETARDATION, FAMILIES & EDUCATION

IN BANGLADESH.

Introduction & Bibliography.

M. Miles

INTRODUCTION

The following notes on mental retardation[1] (MR) in Bangladesh were written early in 1996, in the context of a study of the development cooperation between the Society for Care and Education of the Mentally Retarded Bangladesh (SCEMRB) and the Norwegian Association for the Mentally Handicapped (NFPU).

Historical Background

MR appears in legal, religious, medical and literary texts of ancient India, and in folklore stories. MR may also appear in the rich heritage of old Bengali literature. This historical section glances at MR in Bengal during the past two centuries. Some English-language documentation mentioning MR people in East Bengal[2] exists from the 1770s, when colonial administrators began formal surveys of the territory. Sometimes they found a local ruler with MR, whose affairs were managed (or mismanaged) by his chief officer. From the 1780s there were observations from northern Bengal (e.g. Rangpur District. Saunders, 1789) where many people had goitres. Cretinism was an associated problem, with various levels of MR. The first documented use of iodine to treat goitre in India was at Rangpur in 1825, only five years after the discovery of iodine treatment in Switzerland (Scott, 1825). The Lunatic Asylum at Dacca (Dhaka) recorded some MR patients

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[1] The term 'mental retardation', whatever may be its drawbacks, is widely used among English speakers in South Asia for the condition or construction now called 'intellectual impairment', 'learning disability', etc in some other countries.

[2] With some modifications, the area of British India known as East Bengal became East Pakistan in 1947, then Bangladesh in 1971.

from the 1840s (Green, 1856-57). The Census of British India in 1871-72 surveyed MR (then called 'Idiocy') and mental illness ('Insanity') separately. The Bengal Census found 5,905 'Idiots', and 12,478 'Insane'.

In 1918, India's first special school for children with mental and physical disabilities, "The Children's House", opened at Kurseong, West Bengal. It was a non-government school, headed by Miss Silvia de la Place, who had earlier run an elementary school at Calcutta. In 1919, a Government report stated that

> "It is now universally recognised that defective children can be educated chiefly by means of special apparatus, exercises and discipline. Already remarkable results have been achieved at the Children's House by special methods of sense training." (Annual Report, 1991, p.5)

Psychology was taught at Dacca University from around 1921. By the 1930s, mental measurements were being made using IQ tests in Bengali. A case study of the education of a Bengali MR boy was published by Sinha in 1936. The curriculum at the East Bengal Primary Training College, Mymensingh, included child observation and developmental psychology, with mental testing methods. Journal papers from the 1940s onwards noted that some MR children were 'casually integrated' in ordinary schools, even up to Secondary level. In 1944 a Central Advisory Board of Education report stated that MR children were "not a class radically different from the normal", and that children who scored poorly on IQ tests might have "other attributes which will enable them to play their part as independent and useful citizens." The Board stated that, throughout their school life, MR children

> "should have opportunities of mingling freely with their brighter fellows and of sharing with them such work and pleasures as all children enjoy." (Post-War, 1944, pp.76-82).

A development plan for East Pakistan, 1953-1957, included four schools to cater for 400 'mentally backward' children. That part of the plan was not implemented, probably through lack of resources and because

other demands had higher priority. No formal MR services were opened before the emergence of Bangladesh. Some education reports in the 1950s and 1960s foresaw that progress towards Compulsory Primary Education would bring in some children who would find it hard to cope with the ordinary curriculum. They might keep on repeating the first or second year, blocking up the school. Or they might drop out, without having learnt anything, unless some solution were found. The same problem faces Bangladesh thirty years later.

Development of Information & Formal Services

The historical background before 1971 has been absent from all the existing literature describing MR in Bangladesh, including reports of SCEMRB and NFPU. It is included here to give some perspective to the present, and to help in predicting the direction and speed of changes in the next decade. For the same reason, an English-language bibliography is included, on disability in Bangladesh with emphasis on MR. Most of this documentation has appeared in the past ten years, but so far has had little impact on planning and development of MR services.

At least 20 surveys including data on people with disabilities have been reported from different parts of East Pakistan and Bangladesh, between 1961 and 1995, many of them listing MR among the categories surveyed (see Box 1). Doubtless other small-scale surveys have been carried out, with no published report of the results. None of the survey reports shown here cites more than three of the earlier surveys, and most of them seem to have been planned without any awareness of already existing work. Making allowances for under-reporting and for confusion between MR, mental illnesses, or deafness with emotional and behavioural disturbances, the existing surveys broadly suggest that between 3 and 8 per 1000 of the population may be perceived by their local communities as mentally retarded. The higher figure may be found in areas where goitres and cretinism are more prevalent.

BOX 1. Bangladesh Surveys on Disability, 1961-1995.

The following types of disability survey have been reported formally:

1961 "Blind, deaf and dumb, crippled" in National Census. (Mentioned in Preface, Bangladesh Bureau of Statistics, 1987). Not verified.

1963 Disabled children, Dhaka. (Sobhan, Rahman & Farouk, 1963) Not verified.

1979 Physically disabled children, Bangladesh. (Situation of Physically, 1979. Also digest in: Mia, Islam & Ali, 1981)

1982 Disabled population, Bangladesh. (Bangladesh Bureau of Statistics, 1987)

1985 Beggars with disabilities, Dhaka. (Siddiqui, Qadir, Alamgir & Huq, 1990, pp.278-285. Small part of a much broader study).

1986 Disabled population, Bangladesh. (Bangladesh Bureau of Statistics, 1989)

1986 Lathyrism, Rajshahi and Kushtia districts. (Hamid, Kaul & Akanda, 1986. Refers also to earlier unpublished reports of lathyrism surveys).

1988 MR in Nangalkot Upazila. (Qamaruzzaman, 1988)

1992 Disabilities related to Iodine Deficiency. (Report on Study, 1992)

1992 Childhood disabilities, Bangladesh. (Zaman, Khan, Islam & Durkin, 1992).

1993 Disabilities related to Iodine Deficiency. (Yusuf, Qazi, Islam et al, 1993. Also digest in: Yusuf, Qazi, Islam et al, 1994).

1993 Rural survey for CBR projects. (Hussain, 1996)

1994 Nationwide all-age disability survey. (Bangladesh Bureau of Statistics, 1995a and 1995b).

1994 Disabled village people, Narsingdi. (Nasiruddin & Khan, 1994)

1994 Annual survey of primary schoolchildren, now with disability questions. Min. of Education with Bangladesh Bureau of Statistics. (Report stated to exist in Bangla. Not verified.)

1995 MR in village Bandaikhara. (Sufi, Yamashita & Nazneen, 1996)

Further disability surveys, of which data is not yet formally reported:

1981? Village survey of disability. (Noted by Chowdhury, 1983).

1990, 1993 Blind people, Bhola & Narayanganj Districts. (Bangladesh Drishtihin Foundation. (Quoted in Nasiruddin & Khan, 1994)

1992-1994? Rural survey for CBR projects. (Ahmed, 1994)

1994 (?) Disabled children, Lalmonirhat District. (Briefly described by Ali, 1995).

1994 (?) Disabled children, Dhaka. (Baseline survey for CBR project, Bangladesh Council for Child Welfare internal document).

Thus local community perceptions in Bangladesh may correspond approximately with 'severe MR' as it is sometimes categorised in European countries. Various sources suggest that 'mild MR' is not noticed in the 'simple life of rural communities'. It may be more accurate to say that rural people are quite well aware of differences of mental ability; but since there is plenty of work to be done that requires little learning and no speedy thinking, the mildly MR person is perceived not as 'disabled', but merely as 'slow'.

Formal services for MR people began with a handful of pupils in a special class in the grounds of an ordinary school, Willes Little Flower School, Dhaka, at the start of 1978. This followed meetings in November 1977 among

> "the parents of the mentally retarded children, psychologists, psychiatrists and social workers who had been deliberating and exchanging views on the problems of mentally retarded children..." (Report 1977-81, 1982, p.10)

These meetings resulted in the formation of SCEMRB in December 1977.

The first Report of SCEMRB, for the period 1977-1981, presents some contrast with some subsequent accounts of the Society's origins. According to the first Report (written by one of the founding parents), parents and professionals worked together with a common goal to get services moving for MR children. However,

> "At the time of the formation of the Society when its programmes and projects were adopted, the concept of parents associations and involvement of parents in the activities of the Society was not there. For the first time in our Second National Conference held in June, 1981 Mr Sigurd Gohli Secretary General of the Norwegian Association for the Mentally Retarded defined the concept of parents association and explained how parents could be involved in the various projects and programmes for the welfare of the retarded. Programmes and projects as envisaged in the original scheme of things were to be managed by the professionals under the guidance of the Society." (ibid., p.18)

In the 1990s, the early history has undergone some reinterpretation, along the lines that SCEMRB was always "like NFPU, basically a Parents Organization"; and though some professionals had got involved, "it basically retains the character of a parents' organization" (Barua, 1994).

By 1980, four special education classes had started, the fourth being for slum children at Mauchak, Dhaka-2 (Report 1977-81, pp.18-19). The teachers were a mixture of young psychology graduates and mothers, some of the latter working without salary to start with. The early years apparently saw much support from well-wishers and businesses in Dhaka, many donations of goods, time and money, including substantial amounts from the Government. The Report 1977-81 notes under the heading "Affiliated Bodies" that "The Society has affiliated similar Associations set up in Chittagong and Rajshahi."

More recent service development has been facilitated by the SCEMRB-NFPU Partnership, and is documented in annual reports and conference proceedings. Branches were extended, reaching 36 towns or rural bases by 1995. Bangladesh Institute of Mental Retardation (BIMR) was established, special classes and special schools were opened, vocational workshops were tried out and some success was achieved with agro-based rural training projects. A separate National Institute of Mental Retardation (NIMR) was built, and there are plans for its further extension with Government assistance, to provide more professional services. There are also plans for a Parents Trust to develop rural residential homes, to provide for the MR children of wealthier members after their death.

A separate Dhaka organisation was founded in 1984 by one of SCEMRB's founder members: the Bangladesh Protibondhi Foundation, focused on research-based MR service development with psychologists, special educators, speech therapists and other professionals, and the involvement of some foreign research organisations. Training courses have also been developed at the National Centre for Special Education (NCSE), and the Institute of Education & Research at Dhaka University. Recently there has been a growing interest in 'Community Based Rehabilitation' projects, both in SCEMRB and in other disability organisations.

Lives of MR Bangladeshis in Family & Community

Rural and urban families. **No single study has been reported that covers in depth the daily lives of MR people, whether in rural or urban communities. In fact, there has been little enough serious ethnological work on the everyday lives of Bangladeshis of normal ability. Studies have tended to focus on 'problems', such as poverty, vagrancy, prostitution, squatter settlements, illiteracy, school drop-outs, child labour, absence of family planning, malnutrition, hand-washing practices after defecation, perinatal difficulties, lack of cooking fuel, etc. A few studies have been made of the time use of rural women, and its effects on child-rearing. Yet all these studies do not add up to a picture of the ordinary lives of adults and children in Bangladesh as perceived by themselves rather than by some problem-focused investigator. Still less is known, in a formal sense, about MR people. Individual parents, usually mothers, have told their 'story', which often follows a familiar pattern of early fears, a desperate search for information, slowly gathering an idea of what is 'wrong', a search for professional help and a slow adjustment to having a child with some limitations and some different potentials. Yet these stories are usually connected with a formal service provision, which is available to probably less than 2% of families with an MR member.**

Zaman and colleagues (see bibliography) have studied mothers' self-reported views and attitudes, and also those of siblings of MR children and various professions concerned with disabilities and special education, from the early 1980s up to the present. These studies provide a few glimpses of MR children 'in the background' at home and at school, mostly in urban areas, as reported by their relatives. Qamaruzzaman (1988, pp.13-14) comments briefly on the apparent integration of mildly MR people surveyed in a rural setting. Sufi, Yamashita & Nazneen (1996, pp.137-156) report and speculate a little on the lives of MR people in rural and urban areas, amidst the medical and statistical details of their survey. Possibly some more detailed work exists somewhere in Bangla, but the strong impression is that studies up to now have remained at an elementary level of 'finding out how many there are', padded out with speculation about the 'attitudes' of local communities.

It is assumed that profoundly handicapped infants die young, and that those with mild MR are fairly well integrated in patterns of life that make few intellectual demands. There remain a smaller number who are perceived as a 'problem' - their families may make some efforts to conceal them, or may spend money seeking a cure at shrines or from indigenous healers or quacks. Such assumptions, while plausible, are not based on careful ethnographic studies. Some writers take the optimistic view that there is kindly tolerance in rural areas. By contrast, a study of awareness of Iodine Deficiency Diseases in rural districts (Report on study, 1992) found very many derogatory local names of MR, dwarfism and deaf-mutism (pp.20-21). Attitudes of the community reported by people with goitres, were summed up as "insensitiveness, ridicule and contempt" (p.26). Beliefs about the causes of MR, dwarfism and deaf-mutism also tended to reinforce negative attitudes (pp.41-43).

A disabled person speaking from the National Forum of Organisations Working with the Disabled (NFOWD) asserted that

> "90% of the disabled population of Bangladesh falls within 80% of the total population who live below the poverty line. The physically disabled are being treated as a burden and curse in our society, because this poor section cannot raise any voice and do not get proper education of development. ... If a disabled person is a woman then she becomes "doubly disabled" in our society." (Mohua, 1993)

If that is the case for physically disabled people, it would be safe to assume that MR people have an equally poor public image, and even less control over their own destiny.

MR people also are mentioned in some urban studies in connection with delinquency, begging, prostitution or sexual abuse (e.g. Sufi et al, p.152; Shailo, 1994). Such connections may be plausible for a small number, but they tend to reinforce negative assumptions, which might turn out to be mistaken for the great majority if a careful study were made. (Siddiqui et al, 1990, pp.192, 344, note that the crimes of the poor and weak may be insignificant compared with the rackets of powerful people).

Further, there are a few studies, such as that by Blanchet (1984), which probe the depth and complexity of rural women's beliefs about pollution and birth practices. Such studies indicate that thoughts and beliefs about people whose appearance and/or behaviour is noticeably different from village norms may also be quite varied and complex. Such beliefs are often dismissed by urban researchers as 'superstitious nonsense'. Such dismissals hardly lead to a greater understanding of the realities of rural life for the MR person.

Rural and urban formal services. The formal services that exist tend to be most obviously in the education or training field. Various studies (see Bibliography) suggest that at least 1% of primary schoolchildren are mildly MR in each class, and possibly a higher proportion in the classes I and II. Thus among some 15 million primary schoolchildren at least 150,000, and possibly a much larger number, are likely to be mildly retarded. They are getting their education 'casually integrated' with their schoolfellows, without any official attention or extra expenditure. Their existence was half-recognised by a workshop on Techniques of Identifying Learning Difficulties of Children and Adoption of Method of Remedial Teaching, held at Dhaka in May 1990 (see Begum, 1991).[3]

Additionally, there is some planned 'locational' integration, as in the special classes run by SCEMRB in classrooms or buildings adjacent to those used for ordinary primary schooling. There are a few special schools experimenting with 'reverse integration', whereby the MR children have a sort of priority and 'ownership' of the school, rather than being an insignificant minority attached as an afterthought in a corner. There are some special schools in their own separate building and grounds. There are some home teaching schemes in which a trained teacher visits the home regularly, and others in which a teacher or volunteer gives regular guidance to the mother or other family member on how to teach the MR child at home. There is also a small number of training workshops and

[3] Curiously, this workshop remains unknown to people in the MR field. The term 'learning difficulties' is apparently seen as quite different from 'mental retardation'. (The former has been used in Britain for the past 15 years in place of the latter).

rural vocational activities, mostly for older boys and youths. Considerable experience has accumulated among teachers, trainers, parents and volunteers, during the past 15 years. Unfortunately, little of the knowledge has been formally documented. The comparative effectiveness of the different educational approaches has attracted only few studies (e.g. Zaman & Lutfe Ara, 1990; Akhter, 1994).

Further studies. During the past two centuries, awareness of the needs of Bengalis with mental retardation and other impediments to learning has grown slowly as psychologists, teachers and educational planners grappled intermittently with the problems. The goal of Universal Primary Education has repeatedly been deferred, and there is some awareness that it can never be met without addressing the learning difficulties experienced by many children within traditional pedagogy. External assistance with such efforts, in Bangladesh, would be better grounded with a recognition of the indigenous history of experiences with mental retardation.

For at least the next 20 years, the education and welfare of the majority of mentally retarded people in Bangladesh will be determined mostly by the caring efforts, and level of knowledge, of their immediate relatives and neighbours, with little assistance from formal or professional programmes. Ethnographic studies of the concepts, knowledge, daily lives, activities and priorities of these groups of people, with serious attention to their views and thoughts, could result in project planning and transfers of information and educational resources that respond more closely to their self-perceived needs and wishes.

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(Non-medical. English-language)

This bibliography was prepared in February 1996, following a four-week consultancy in Bangladesh concerned with mental retardation, childhood disability and information resources. While *far from comprehensive*, it may be of some assistance to concerned people in the disability field. For more comprehensive *Indian* material, see Venkatesan & Vepuri (1995).

Part 1: **Directly concerns Mental Retardation and Childhood Disabilities.**

Part 2: **Other relevant material, e.g. child-rearing, rural women, primary education, etc. (This could be much extended. The aim here is to indicate some of the types of relevant work that has been done).**

Part 3: **Some historical references, from a journal paper on Mental Retardation in East Bengal, 1771-1971.**

A few conference abstracts are listed, where proceedings are likely to be published and where the topics have little other coverage.

Light annotation is given, where the title is not explicit, or where further information may be useful.

Abbreviations

BRAC	**Bangladesh Rural Advancement Committee, Dhaka.**
CBR	**Community Based Rehabilitation**
Ed., Eds.	**Editor(s), Edited by**
MR	**Mental Retardation**
NFPU	**Norwegian Association for Mentally Handicapped, Rosenkrantzgt. 16, N-0169, Oslo, Norway.**
q.v.	***quod vide* (which see)**
SCEMRB	**Society for Care and Education of the Mentally Retarded Bangladesh, 4/A Eskaton Garden, Dhaka 1000.**
VHSS	**Voluntary Health Services Society, GPO Box 4170, Dhaka 1000.**

PART I

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